



**NACDD**

National Association of Councils  
on Developmental Disabilities

## 2017 ANNUAL CONFERENCE



**A QUALITY LIFE:**  
COUNT ME IN!

July 13-14, 2017  
Hotel RL Salt Lake  
Salt Lake City, Utah

# Table of Contents

<b>WELCOME .....</b>	<b>4</b>
<b>CONFERENCE INFORMATION .....</b>	<b>5</b>
<b>HOTEL MAP .....</b>	<b>6</b>
<b>SPONSORS .....</b>	<b>7</b>
<b>CONFERENCE AGENDA AT-A-GLANCE.....</b>	<b>8</b>
<b>DAILY SCHEDULES.....</b>	<b>9</b>
<b>SPEAKERS AND PRESENTERS.....</b>	<b>17</b>
<b>NACDD STAFF .....</b>	<b>32</b>
<b>NOTES.....</b>	<b>33</b>

July 13, 2017

Dear Friends,

**Welcome to NACDD's Annual Conference, "A Quality Life: Count Me In!"**

On behalf of the National Association of Councils on Developmental Disabilities, we welcome you all to the 2017 Annual Conference! We are very excited about this year's theme, "A Quality Life: Count Me In!" Through this theme, we will explore the many ways we work across the DD Council network and with other stakeholders to ensure that every individual's voice and needs count in the work we do.

The authentic voices of self-advocates, along with caregivers, family members, friends, and professionals are integral to the design of our work across Councils. As Councils on Developmental Disabilities, we are charged with working within communities to improve systems so that they work smoothly and seamlessly to ensure that all people are supported and able to live their best life possible in the community.

This year's conference program features many great presenters who will speak to how we ensure that all voices are counted. From our work in support of training and encouraging self-advocacy, to making sure that policymakers know what we want for our health care, education and employment systems, we will learn together how to make sure our voices are heard loud and clear.

We are excited to bring you a program filled with tremendous speakers from across the country who will share best and most promising practices for how to make our voices count. We will hear from self-advocates, national organization partners and of course, our outstanding DD Councils. We know you will all learn a great deal and go home energized and focused.

We are grateful to the NACDD Member Services Committee and the Conference Planning & Review Committee, both chaired by Valarie Bishop, which helped plan and organize this year's conference. We also thank Claire Mantonya and the staff at the Utah Council on Developmental Disabilities for their support in helping us host a great meeting in Salt Lake City, Utah. Most of all, we want to thank you for taking the time and making the effort to join us this week.

Thanks for being "Counted In" by attending the NACDD Annual Conference!

Best wishes,



Shannon Buller  
Acting President



Donna Meltzer  
CEO

# Conference Information

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## Need Information or Assistance?

The NACDD staff will be wearing black lanyard staff badges. Please come to the Registration Table (Foyer) if you need assistance. We're happy to help!

## Conference Evaluation

Please help us improve on the NACDD Annual Conference by completing an evaluation which will be distributed on Friday. An additional link will be provided on the NACDD website following the conclusion of the conference.

## Audio-Visual Equipment

If you are a speaker who needs assistance with the audio-visual equipment, a member of the NACDD staff will be happy to assist you or connect you with hotel technology staff that can help.

## Navigating the Meeting Space

Please see the hotel floor plan on page 6 to identify the location of the meeting spaces, elevators and emergency exits. Please look for signage that indicates the name of each session.

## Accommodations

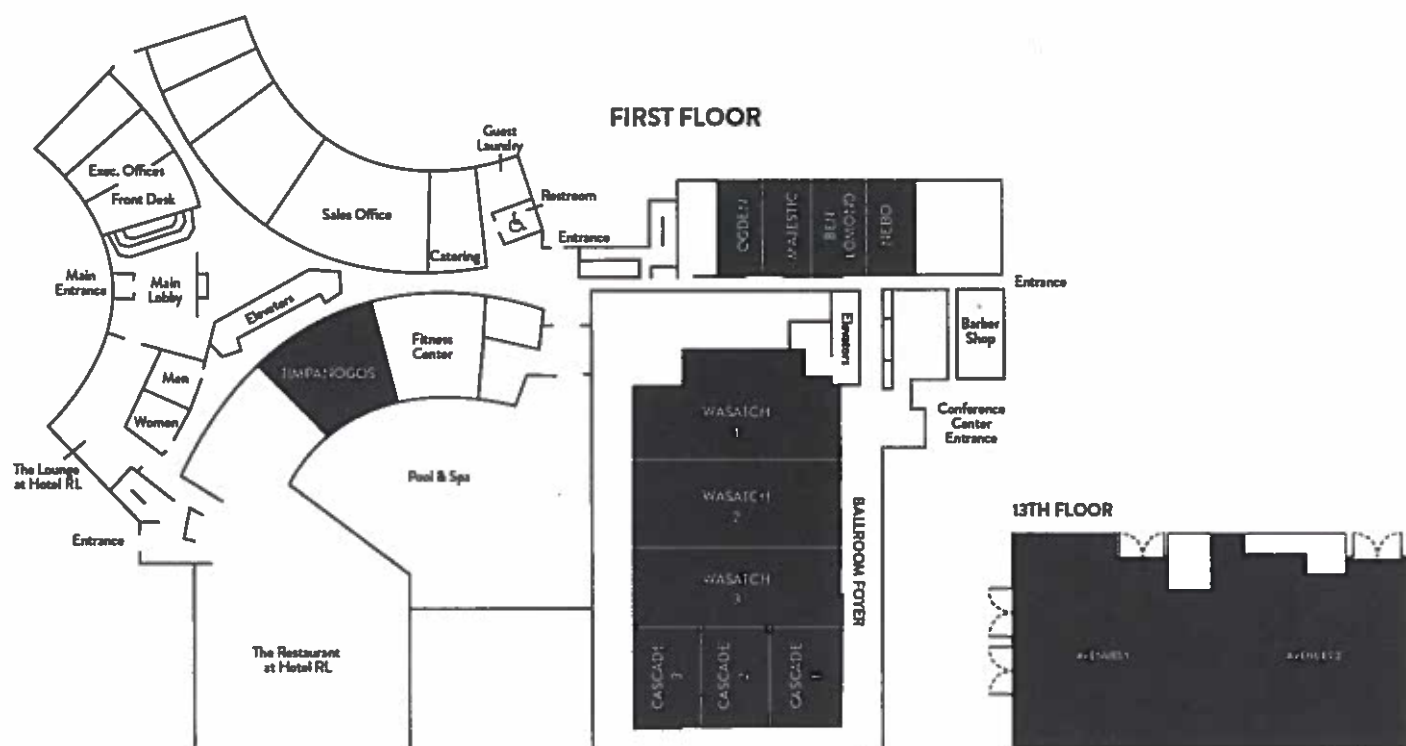
We will have CART transcription available during the plenary sessions and lunches. For any accommodations not requested in advance of the conference, please see NACDD staff at the Registration Table to assist you in meeting an on-site request.

## Food in the Hotel

The Hotel RL Salt Lake has one dining option on-site which offer many options for breakfast, lunch and dinner. Please check your hotel guide directly for hours of operation and menu details. Additional food options are available within a short distance from the hotel.



# Hotel Map



Thank you to our sponsors!





# Conference Agenda At-A-Glance

Tuesday, July 11, 2017		
11:00 a.m. – 5:00 p.m.	Registration	Foyer
9:00 a.m. – 1:00 p.m.	NACDD Board of Directors Meeting	Timpanogos
11:00 a.m. – 1:00 p.m.	Territories Meeting	Cascade 1/2
1:30 p.m. – 5:30 p.m.	Technical Assistance Institute Day 1	See separate agenda
Wednesday, July 12, 2017		
7:30 a.m. – 2:00 p.m.	Registration	Foyer
8:45 a.m. – 5:15 p.m.	Technical Assistance Institute Day 2	See separate agenda
5:30 p.m. – 7:30 p.m.	Welcome Reception – Sponsored by Anthem (Open to TAI and Annual Conference Participants)	Avenue 1/2
Thursday, July 13, 2017		
7:30 a.m. – 2:00 p.m.	Registration	Foyer
7:30 a.m. – 8:15 a.m.	Breakfast	Foyer
8:15 a.m. – 8:45 a.m.	Opening and Welcome of Annual Conference	Wasatch 1/2/3
8:45 a.m. – 10:45 a.m.	Plenary I – Advocates Living Their Best Life: Self-Determination and Alternatives to Guardianship	Wasatch 1/2/3
10:45 a.m. – 11:00 a.m.	Break	
11:00 a.m. – 12:15 p.m.	Supporting Self-Advocacy Concurrent Sessions (4) ✓	Cascade 1, 2, 3, Timpanogos
12:15 p.m. – 12:30 p.m.	Break – Move into Awards Lunch	
12:30 p.m. – 2:30 p.m.	CEO Awards Luncheon – Sponsored by OPTUM	Wasatch 1/2/3
2:30 p.m. – 2:45 p.m.	Break	
2:45 p.m. – 4:00 p.m.	Plenary II – Health in the New World Order	Wasatch 1/2/3
4:00 p.m. – 4:15 p.m.	Break	
4:30 p.m. – 5:45 p.m.	Healthcare Concurrent Sessions (4) ✓	Cascade 1, 2, 3, Timpanogos
5:45 p.m. – 8:00 p.m.	Dinner on your own	
Friday, July 14, 2017		
7:30 a.m. – 9:00 a.m.	Breakfast and General Assembly	Wasatch 1/2/3
9:00 a.m. – 9:15 a.m.	Break	
9:15 a.m. – 10:30 a.m.	Plenary III – Serving the Community	Wasatch 1/2/3
10:30 a.m. – 10:45 a.m.	Break	
10:45 a.m. – 12:00 p.m.	Community Services Concurrent Sessions (4)	Cascade 1, 2, 3, Timpanogos
12:00 p.m. – 1:15 p.m.	Lunch	Wasatch 1/2/3
1:15 p.m. – 1:30 p.m.	Break	
1:30 p.m. – 2:45 p.m.	Plenary IV – In an Emergency: Nothing About Me, Without Me!	Wasatch 1/2/3
2:45 p.m. – 3:00 p.m.	Wrap Up and Closing Remarks	Wasatch 1/2/3

# Daily Schedules

*Tuesday, July 11, 2017*

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**11:00 a.m. – 5:00 p.m.**

**Registration**

*Foyer*

**9:00 a.m. – 1:00 p.m.**

**Board of Directors Meeting**

*Timpanogos*

**11:00 a.m. – 1:00 p.m.**

**Territories Meeting**

*Cascade 1/2*

**1:30 p.m. – 5:30 p.m.**

**AIDD Technical Assistance Institute Day 1**

*See separate agenda*

*Wednesday, July 12, 2017*

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**7:30 a.m. – 4:00 p.m.**

**Registration**

*Foyer*

**8:30 a.m. – 9:30 a.m.**

**Breakfast**

*Foyer*

**8:45 a.m. – 5:15 p.m.**

**AIDD Technical Assistance Institute Day 2**

*See separate agenda*

**5:30 p.m. – 7:30 p.m.**

**Welcome Reception**

*Avenue 1/2 (13<sup>th</sup> floor)*



**7:30 a.m. – 2:00 p.m.**

**Registration**

*Foyer*

**7:30 a.m. – 8:15 a.m.**

**Breakfast**

*Foyer*

**8:15 a.m. – 8:45 a.m.**

**Opening and Welcome of Annual Conference**

*Wasatch 1/2/3*

**Valarie Bishop**, South Carolina Council on DD

**Claire Mantonya**, Utah DD Council

**Donna Meltzer**, NACDD

**8:45 a.m. – 10:45 a.m.**

**Plenary I**

**Advocates Living Their Best Life: Self-Determination and Alternatives to Guardianship**

*Wasatch 1/2/3*

Participants will view “Body and Soul: Diana and Kathy” with Diana Braun and Alice Elliott. Following the film, there will be a discussion Diana on her life and her advocacy. In addition, participants will hear from representatives of North Carolina and Texas about the major headway they are making in providing alternatives to guardianship so that people with I/DD are living independently with self-determination, and self-reliance.

Ms. Kendall Fields will show how North Carolina is using the Collective Impact framework, and Jeff Miller will discuss the Texas guardianship process, to effect change in each state’s adult guardianship system so that individuals with disabilities can more fully exercise their right to make their own decisions.

**Diana Braun**, Illinois Council on DD

**Alice Elliott**, Welcome Change

**Linda Kendall Fields**, Jordan Institute for Families, UNC Chapel Hill

**Jeffrey Miller**, Disability Rights Texas

**Moderator: Beth Stalvey**, Texas Council for DD

**10:45 a.m. – 11:00 a.m.**

**Break**

**11:00 a.m. – 12:15 p.m.**

**Supporting Self-Advocacy Concurrent Sessions (4)**

**① My Voice Counts: Supports vs. Control**

*Cascade 1* ✓

People with disabilities are continuing to learn more about self-determination, how to find their voices and are increasingly interested in finding new ways to lead a supported life. In this presentation, self-advocates, family members and professionals will learn the differences between guardianship and supported decision-making strategies. Participants will gain real life tools to assist when developing circle of supporters, recognize the importance of supported decision making agreements and how this model of support can assist with medical, financial, housing, educational and personal decisions that have a direct influence over a person’s quality of life.

**Eric Stoker**, Utah DD Council

**Tamera Dalton**, Utah DD Council

**Kelly Holt**, Utah DD Council

**Moderator: Valerie Breen**, Florida DD Council

**② Trainings to Become More Empowered**

*Cascade 2*

Participants in this session will hear from two successful training tools that teach advocates to

use their voice to speak about the issues that matter most to them.

The New York State blended learning approach to teaching Partners in Policymaking to self-advocates and families has been able to mitigate barriers to attending Partners training, thereby expanding the Partners reach and network; meet Partners Graduates online and take a peek at the online course format!

Over the past four years, Opening Minds, Opening Doors has given voice to more than 50 self-advocates from across the state of Texas. In our grant project awarded by the Texas Council for Developmental Disabilities, we translated an autobiographical performance process into a six-week speaker workshop designed to prepare individuals with developmental disabilities to deliver their own conference presentations. Now, after a dozen classes and facilitating more than 20 self-advocate presentations at conferences around the state, we have a strong curriculum and a guide for prospective workshop facilitators to bring this work to other states and experience the power of this work firsthand.

**Carol Blessing**, Cornell University Yang-Tan Institute on Employment and Disability

**Jessica Guerrero**, VSA Texas

**Celia Hughes**, VSA Texas

**Moderator: Kimberly Mercer-Schleider**, Illinois Council on DD

### ● Council Activities to Promote Self-Advocacy *Cascade 3*

Participants will hear from three distinct programs from across the US that offer self-advocates leadership training, skill-building training, community inclusion, and social connections. Each program will discuss the



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CARE HAPPENS  
WHEN WE ALL WORK  
**TOGETHER**

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**We Salute You for  
Helping to Build a Better  
Community.**

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**Anthem**



potential for replication in your own states or communities.

EQUIP, funded by the South Carolina Council, is a working model of peer-to-peer mentorship and skill building in self-advocacy, disability pride, communication, goal setting, and leadership for young adults with disabilities ages 13-28 in South Carolina. The project lead will discuss the programmatic context underpinning the program as well as the importance of the collaborative efforts of its many state partners.

The Advocate Leadership Academy program is using peer coaching and a set of eight leadership competencies developed by an advocate with disabilities as a part of his LEND project. The goal is to provide people with disabilities leadership training so they can directly engage with the needs they face in their own communities.

This presentation will also introduce you to Next Chapter Book Club – the largest community-based book club program in the world for individuals with intellectual and developmental disabilities. Awarded the "Innovations in Learning" Prize by the National Book Foundation, Next Chapter Book Club provides a weekly opportunity for social connections, community inclusion, self-advocacy/self-determination, life-long learning, and FUN.

**Susan Berg**, Chapters Ahead

**Daniel Ekman**, New Mexico DD Planning Council

**Derrick Means**, Able South Carolina

**Erica Powell**, Able South Carolina

**Moderator: Valarie Bishop**, South Carolina Council on DD

### ● The Role of the Family

*Timpanogos*

This session will discuss the role of the family in and how disabilities affect different members of

"Unity is strength... when there is teamwork and collaboration, wonderful things can be achieved."

– Mattie Stepanek



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the family, whether it be a person with a disability or a parent with a disability or the family members of a person with a disability.

**Anna Brady**, Sibling Leadership Network

**Mindy Braga**, Sibling Leadership Network

**Adonis Brown**, North Carolina Council on DD

**Laura Henrie**, Disability Law Center

**Paulena Rymer**, TURN Community Services

**Erin Taylor**, Oklahoma DD Council

**Ann Trudgeon**, Oklahoma DD Council

**Moderator: Arlene Poncelet**, Executive Director,  
South Dakota Council on DD

**12:15 p.m. – 12:30 p.m.**

**Break – Move to Awards Lunch**

**12:30 p.m. – 2:30 p.m.**

**Champions of Equal Opportunity Awards Luncheon (sponsored by OPTUM)**

*Wasatch 1/2/3*

Join NACDD as we honor the Champions of Equal Opportunities (CEO) 2017 Awardees. Each year, NACDD honors one national policymaker and one self-advocate who has gone above and beyond to promote inclusion and full integration in the community for individuals with disabilities.

**2:30 p.m. – 2:45 p.m.**

**Break**

**2:45 p.m. – 4:00 p.m.**

**Plenary II**

**Health in the New World Order**

*Wasatch 1/2/3*

This 3 speaker panel will discuss where we are now in healthcare specifically related to federal policy, Medicaid, and Managed Care and how these changes will impact people with developmental disabilities.

**Alison Barkoff**, Center for Public Representation

**Andrew Sperling**, National Alliance on Mental Illness

**Julie Weinberg**, UHC Community and State

**Moderator: Donna Meltzer**, NACDD

**4:15 p.m. – 5:45 p.m.**

**Healthcare Concurrent Sessions (4)**

● **Managed Care from a Healthcare Company**  
*Cascade 1*

Managed care is increasingly being leveraged by states to administer Medicaid programs. With this movement to managed care, individuals receiving Medicaid services and the providers and organizations that serve them are engaging with health plans in new ways. Navigating the landscape of Medicaid managed care can seem daunting and challenging to find a place to begin developing relationships. Join us for a candid conversation about why states are interested in managed care and what DD councils and advocates may want to consider as programs are being designed. During the panel conversation hear from collaborators in Kansas – one representing a health plan and one representing the Kansas DD Council – as they describe the journey their state has been on to establish managed care that works for individuals with ID/DD, their families and the system that supports them. We will have significant opportunity for conversation and questions as we look to share lessons learned and improve programs and collaborations.

**Steve Gieber**, Kansas Council on DD

**Angie Reinking**, United HealthCare Community Plan of Kansas

● **We Can All Be Fit for Life**  
*Cascade 2*

SOS Health Care will be presenting on their Fit for Life program which provides fitness and

nutrition classes to individuals with autism and various developmental disabilities. The focus of the presentation will be on the activities performed in the classes as well as the importance of the health and wellness of individuals with disabilities. They tend to only be seen as their disability and their health and wellness can be overlooked. Fit for Life ensures that individuals are active and educated when it comes to health and wellness.

**Sarah Pope**, SOS Healthcare, Inc.

**Diane Owens**, SOS Healthcare, Inc.

**Heather Hardee**, Fit for Life Assistant Instructor

**Moderator: Kirsten Murphy**, Vermont DD Council

### ● The Connection Between Down Syndrome and Alzheimer's Disease

*Cascade 3*

Alzheimer's disease and Down syndrome share a genetic connection, leading to the increased risk of dementia at an earlier age. Understandably, many families and caregivers are especially worried about this possibility, which is one reason why this topic is covered in detail in this session. Getting accurate information and education about the risk of Alzheimer's disease is an important way of empowering oneself to prepare for the future.

**Khadijah Farmer**, National Down Syndrome Society

**Kate Macklin**, Delaware Valley Chapter of the Alzheimer's Association

**Pat Maichle**, Delaware DD Council

**Sara Weir**, National Down Syndrome Society

### ● Advocacy to Affect Policy Impacts

*Timpanogos* ✓

Coalition advocacy requires that people who are most affected by policy decisions are involved in

the design, implementation and regulation of policy; it is essential to engage people with disabilities who have often been excluded from policy decisions. We will focus on effective strategies that advocates can use to have an impact on public policy as well as ways DD Councils can support advocates to do so.

This session will explore tools one state has used to engage the grassroots on effective advocacy that helped both the disability community and policymakers better understand Medicaid programs, how long-term supports work, and what's at stake when changes happen without a stakeholder voice. We will share low-cost strategies like using social media and simple graphics to convey complex ideas.

**Kelly Friedlander**, Community Bridges Consulting Group

**Nessie Siler**, North Carolina Council on DD

**Beth Swedeen**, Wisconsin Board for People with DD

**Moderator: Mariel Hamer**, Illinois Council on DD

**5:45 p.m. – 8:00 p.m.**

**Dinner on your own**



**7:30 a.m. – 9:00 a.m.**

**Breakfast and General Assembly**

*Wasatch 1/2/3*

**9:15 a.m. – 10:30 a.m.**

**Plenary III**

**Serving the Community**

*Wasatch 1/2/3*

Community services are vital to people with I/DD so that they have full access to the community in which they live.

Title II of the Americans with Disabilities Act (ADA), as interpreted by the Supreme Court's decision in *Olmstead v. L.C.*, requires public entities to administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities. This session will provide an overview of DOJ's activities in enforcing the integration mandate and highlight DOJ enforcement matters that have enabled people with disabilities to move from segregated settings into supported housing and other integrated settings.

Project HIRE (Helping Individuals Reach Employment) is a grant funded by the Texas Council for Developmental Disabilities to support 52 individuals between the ages of 18 and 25 with DD to pursue a post-secondary education at South Texas College and gain employment.

The Florida Transportation Voucher Pilot Program has proven to be a cost-effective, self-sustaining model with significant return on investment and great potential for further replication. The program is an urban model for providing 24-hour transportation services to individuals with I/DD.

**Eliza Dermody**, Department of Justice  
**Santa Peña**, South Texas College

**Sonia Quintero**, Communication Access Ability Group

**Sheila Gritz-Swift**, Florida DD Council

**Moderator: Alison Barkoff**, Center for Public Representation

**10:30 a.m. – 10:45 a.m.**

**Break**

**10:45 a.m. – 12:00 p.m.**

**Community Services Concurrent Sessions (4)**

**❶ Collaborative Leadership to Advance Disability Policy**

*Cascade 1*



This session will provide an overview of two model collaborative efforts at the state and national levels to advance disability policy: Senator Hatch's Utah Advisory Committee on Disability Issues; and The Disability and Aging Collaborative. History, structure, challenges, and successes will be shared. The session will also discuss coordination between these coalitions and collaboration with Senator Hatch's office to advance long-term services and supports policy.

**Joe Caldwell**, National Council on Aging

**Jeff Sheen**, Utah State University (*Invited*)

**Moderator: Aaron Carruthers**, California State Council on DD

**❷ Pathways to Careers Initiative**

*Cascade 2*

SourceAmerica's Pathways to Careers is a systems change initiative designed to enable individuals with I/DD and autism spectrum disorders to have real options for competitive, integrated employment in their community. This session will speak about Pathways' customized



employment approach and how participants are being offered internships and career-oriented employment options that match their individual skills, interests and abilities, facilitating greater inclusion in their communities, greater independence and “A Quality Life!”

**Therese Fimian**, SourceAmerica

**Amy Stapely**, SourceAmerica

**Vickie Calder**, PARC Pathways to Careers

**Ashtin Miller**, Pathways to Careers Participant

**Brittany Chiles**, Parent to Pathways Participant

**Kelly Mayo**, Ashtin’s Internship Supervisor

**Moderator: Ann Trudgeon**, Oklahoma DD Council

### ● **First Responder Disability Awareness Training**

*Cascade 3*

Niagara University Disability Awareness Training has developed the nation’s only comprehensive training for first responders in how to accurately and appropriately recognize, identify, and interact with individuals with disabilities. The program originated from a grant from the NYS DDPC and is firmly established in New York. Missouri CDD also funded a grant that now has the program under way in that state. NU will explain the program, it’s content, and the process to securing and establishing it in other states in the nation.

**David Whalen**, Niagara University

**Moderator: Heidi Lawyer**, Virginia Board for People with Disabilities

### ● **The HCBS Settings Rule: Updates and Strategies**

*Timpanogos*

The Home and Community Based Services (HCBS) Settings Rule provides an opportunity for

states to move their systems towards more integrated and individualized services. Alison Barkoff will present on recent guidance from the federal government about the Rule and discuss the status of states’ implementation. She will facilitate a discussion of strategies DD Councils are using in their states to educate and engage people with DD, families and other stakeholders in their states’ implementation.

**Alison Barkoff**, Center for Public Representation

**12:00 p.m. – 1:15 p.m.**

**Lunch**

*Wasatch 1/2/3*

**1:15 p.m. – 1:30 p.m.**

**Break**

**1:30 p.m. – 2:45 p.m.**

**Plenary IV**

**In an Emergency: Nothing About Me, Without Me!**

*Wasatch 1/2/3*

Councils can play an important role affecting systems change in emergency management. They can ensure individuals with I/DD have the tools to help themselves and others to put personal plans in place, provide information that can lead to policy changes in emergency preparedness, response and recovery plans, and even participate in exercising plans at all levels.

**Kimberly Berg**, New York State DD Planning Council

**Vicky Davidson**, Missouri DD Council

**Russell Lehmann**, Nevada Governor’s Council on DD

**Andrew Morris**, Administration on Community Living

**David Whalen**, Niagara University

**2:45 p.m. – 3:00 p.m.**

**Wrap-up and Closing Remarks**

*Wasatch 1/2/3*

# Speakers and Presenters

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## **Alison Barkoff**

Alison Barkoff is the Director of Advocacy at the Washington, D.C. office of the Center for Public Representation. She works on policy and litigation related to community integration and inclusion of people with disabilities, including Olmstead enforcement, Medicaid policy, employment, housing, and education. She serves as a co-chair of the Long Term Services and Supports Task Force of the Consortium of Citizens with disabilities and has helped lead CCD's advocacy to protect Medicaid. She also served as an appointed member of the federal Advisory Committee for Competitive Integrated Employment of People with Disabilities and helped start and lead an Inclusion Task Force in her home school district. From 2010 to 2014, she served as Special Counsel for Olmstead Enforcement in the Civil Rights Division of the Department of Justice. In that position, she led the Division's efforts to enforce the right of individuals with disabilities to live, work and receive services in the community. During her time with the federal government, Ms. Barkoff also worked with the Centers for Medicare & Medicaid Services on finalizing rules governing Medicaid-funded community-based services and with the Department of Labor on implementation of new fair wage rules in Medicaid-funded disability service systems. She has previously worked at the Bazelon Center for Mental Health Law and at a number of other public interest organizations on Olmstead enforcement, disability discrimination, Medicaid, employment, and special education cases. She has an adult brother with an intellectual disability and has been involved in disability advocacy most of her life. She speaks nationally and publishes articles on disability and civil rights issues.

## **Kimberly Berg**

Kimberly Berg is a Program Planner for the Individuals and Families Committee, at the New York State Developmental Disabilities Planning Council. She has worked in the field for nearly 10 years, beginning as a direct support professional at a residential treatment facility, as well as working under the Director of Culture Change Initiatives at the Office for People with Developmental Disabilities, before coming to the DDPC. She has worked in various capacities at the DDPC, and thoroughly enjoys working within the DDPC's collaborative approach to developing innovative projects and participating in meaningful outreach and advocacy.

## **Susan M. Berg**

Susan began as Executive Director of Chapters Ahead in November 2015 and is leading the strategic expansion of Next Chapter Book Club. An early participant in the social entrepreneurship movement, she has spent more than 20 years guiding fundraising, marketing and communications campaigns for nonprofit organizations and educational institutions, including the Cystic Fibrosis Foundation, Cincinnati Children's Hospital Medical Center and Ohio University. Susan was the recipient of several awards for her work as the Founder and Executive Director of a community-based, transitional vocational program for individuals with I/DD, including Ernst & Young's "Socially-Responsible Entrepreneur of the Year" and the Columbus, Ohio YWCA's "Women of Achievement." Her undergraduate and graduate studies were in English and Journalism and she is a long-time freelance reporter for American City Business Journals.

### **Valarie Bishop**

Valarie Bishop is currently the Executive Director of the South Carolina DD Council. She has extensive experience providing leadership for services to individuals with DD and their families. She is an experienced grant writer and manager. Prior to joining the Council, she was a Chief Operations Officer for a Mental Health Authority in Michigan where she managed services across a four-county region for all populations. She holds a Master of Arts Degree from Central Michigan University with a Counseling and Community Administration/Leadership focus and a bachelor's degree from the University of Florida with a major in psychology. She is the current chair of the NACDD Member Services Committee and is a strong advocate for self-determination and independent living.

### **Carol Blessing**

Carol Blessing, LMSW, has over 30 years in the field of disability services in both direct practice and management capacities. She is on faculty at the Yang-Tan Institute on Employment and Disability in the School of Industrial and Labor Relations at Cornell University where she leads systems impact projects aimed at supporting the full inclusion of people with disabilities in typical community life. Carol is the project director for the New York State Partners in Policymaking leadership program. Additionally, she developed and facilitates the landmark Citizen-Centered Leadership series, an international resource in cultivating personal leadership in promoting full inclusion through authentic person-centered practices with people with disabilities and their allies.

### **Anna Brady**

Anna Brady is a doctoral candidate at Utah State University and has a Master's degree in Special Education. Anna has two brothers with various disabilities and worked as a special education teacher at the high school/transition level before moving to Utah to work on her PhD program. Her research interests include interventions to increase people with disabilities' independence, as well as supporting adult siblings of people with disabilities. She has worked with people with all ages and types of disabilities in school, recreation, home, and work settings.

### **Mindy Braga**

Mindy Braga, first and foremost, is the younger sister of Brandon Braga, who has deaf/blindness and many other disabilities. Rather than shy away from her brother's challenges, Mindy has truly taken this calling head on. She and her parents founded a support group for siblings of children with disabilities known as Super Incredible Brothers and Sisters or SIBS. They meet quarterly for a night of fun, expression and networking. Mindy also helped her family open Bear-O Care, a center for adults with multiple disabilities. Since the age of 10, Mindy has spent her summers volunteering at the Kari Sue Hamilton School for people with disabilities. Mindy has spoken at several conferences, including the Utah deaf/blind parents conference and the International CHARGE Syndrome conference in Chicago, IL. She has a true love for everyone, regardless of their abilities and she loves to share her message with everyone.

### **Diana Braun**

Since *Body & Soul: Diana & Kathy* was completed, Diana Braun has traveled thousands of miles to screen the film and talk about advocacy, self-determination and independent living. She presented at the Shafallah Center in Doha, Qatar on the topic of disaster preparedness for people with disabilities.

For the US State Department, Diana traveled with director, Alice Elliott, to Uzbekistan where they screened *Body & Soul: Diana & Kathy* at the US Embassy and a local disability center. Diana has initiated many screenings for small groups and public libraries. At The Arc National Convention in 2015, she presented *ACTIVATE HERE!*, an online, self-advocacy training video in which Diana appears. Since Kathy died in 2009, Diana works part-time for the Illinois Department of Human Services. She is also a seasonal volunteer at Our Lady of the Snows retreat center in Belleville, Illinois. With her hobby of knitting, she created a small business selling hand-made hats, scarves and placemats. She takes and fills orders for special colors. She has served on the Illinois DD Council and most recently has spent several months volunteering to help an ill friend. Her 40 years of experience as a caretaker gives her insight into the roles of the service provider and recipient.

### **Adonis Brown**

The early parts of Adonis' life took place before the Americans with Disabilities Act of 1990 (ADA), or the Individuals with Disabilities Education Act (IDEA) formerly the Education for all Handicapped Children Act of 1975, or the Rehabilitation Act. Despite the barriers, stigmas, and narrow thinking of that time, he persevered. In April 2010, Adonis completed a bachelor's degree in Psychology from Ashford University. He later went on to continue his education with an MBA degree with specializations in Organizational Leadership and Health Care Administration also from Ashford.

He has dedicated his life to the ideals of independent living, community inclusion, and socioeconomic and political empowerment of persons living with disabilities. Between 2001 and 2009, Adonis served on the Durham Mayor's Committee for Persons with Disabilities. Through his leadership, they established Durham's first MCPD Office/Disability Resource Center in City Hall, published the first official newsletter, and led the committee to greater focus on the disability community. In November 2015, Mr. Brown was elected to the First in Families of North Carolina (FIFNC) Board of Directors. Adonis has served as a Council Member on the North Carolina Council on DD since 2007 in many leadership roles, currently serving as a Co-Vice Chair. Adonis currently serves as President of The Arc of North Carolina Board of Directors.

### **Vickie Calder**

Vickie Calder is the Program Director for PARC Pathways to Careers. Prior to joining the Pathways Team at PARC, Vickie was with the Davis School District for 31 years as a Manager for the Data Processing Department. Vickie has many years of experience working with people with disabilities, both professionally and in her personal life, and has made it her personal mission to help create a society where people with disabilities can achieve their full individual potential.

### **Joe Caldwell**

Joe is Director of Long-Term Services and Supports at the National Council on Aging (NCOA). He leads the Disability and Aging Collaborative. Joe has over 20 years of experience in the field of disability and aging as a researcher and policy expert. Prior to NCOA, he was a Kennedy Fellow with the Senate HELP Committee, where he worked on the CLASS Act and other LTSS legislation. He also worked on federal disability policy for the Association of University Centers on Disability (AUCD). Joe is also an Adjunct Assistant Research Professor at the University of Illinois at Chicago, where he earned his doctorate in Disability Studies. He has an extensive research background in evaluation of community-based programs serving individuals with disabilities and family caregivers and has published widely on outcomes of self-directed programs, family support

interventions, the self-advocacy movement, and Home and Community-Based Services quality. He serves on the boards of the Consortium for Citizens with Disabilities and National Alliance for Caregiving.

### **Brittany Chiles**

Brittany Chiles is an IRS Employee and Ashtin's Mom. Brittany has been such a great support to Ashtin in helping her become successfully employed.

### **Tamera Dalton**

Tamera Dalton was born and raised in Parowan before moving to Bountiful, Utah with her mother and stepfather. She is a straight shooter, hardworking advocate, not only for herself but for other people with disabilities. For many years, she was an active part of the disability movement through her volunteering efforts with the Utah DD Council and Utah Division of Services with Disabilities, where she brought her voice to the reality of services and supports. She also has worked for the Disability Support Center for Families and in 2016 and held the position of Presentation Coordinator for the Speaker's Network. "Cannot" is not part of her vocabulary, which makes her an effective speaker when it comes to educating community members about the challenges that people with disabilities face.

### **Vicky Davidson**

Vicky Davidson has over 30 years of experience as a service provider, working toward statewide systems change and policy development that impacts individuals with developmental disabilities and their families. More importantly, she is a mother and family member to individuals with disabilities.

Following Hurricane Katrina and while working for the Missouri DD Council, Vicky became active in the emergency management arena with a focus of working with individuals with disabilities, their families and providers of services in which she provided training on the topics of mitigation, preparedness and community involvement of people with disabilities.

Vicky left the Missouri DD Council and served as a Manager of the Emergency Operations Coordination Unit with the Department of Health and Senior Services/Center for Emergency Response and Terrorism for several years. She has worked with the State Emergency Management Agency as a trainer and course manager for the G-197 Emergency Planning for Special Needs Populations as well as the current course, Functional Needs Support Services for General Population Shelters.

Vicky was asked to return to the Missouri DD Council as the Executive Director where she continues to work with the SEMA as a trainer and course manager for the FNSS course as well as the Functional Assessment Support Team (FAST) training. As a chair of the Functional and Access Needs Committee, she serves as chair for the Technology Work and Innovations Group that is looking at incorporating technology that will include persons with disabilities.

### **Eliza Dermody**

Eliza Dermody is a trial attorney in the Disability Rights Section of the Civil Rights Division at the U.S. Department of Justice. Her work focuses on enforcing the requirement, under Title II of the Americans with Disabilities Act, that public entities administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities. At DOJ, she has worked on cases involving



the unjustified segregation of people with I/DD, medically fragile children, and adults with serious mental illness.

### **Daniel Ekman**

Daniel Ekman is the Program Manager at the New Mexico Center for Self Advocacy at the DD Planning Council. He graduated with Honors with a Master's in Special Education from the University of New Mexico and won the 2013 Outstanding Student with a Disability Award from the Southwest Conference on Disability. He also received the 2011 Bob Thomas Award for Disability Advocacy from The Arc of New Mexico and will receive the Liz Thomson Award from Partners in Policymaking. He is also a current Diversity Fellow with the Association for University Centers on Disability. He has collaborated and volunteered with many organizations including the Jemez Vocational Rehabilitation Advisory Council, the New Mexico Autism Society, People First of New Mexico, New Mexico Young Disability Leaders, and New Mexico Allies for Advocacy among others.

### **Alice Elliott**

Alice Elliott teaches filmmaking at New York University's Tisch School of the Arts and is a media diversity consultant for corporations and nonprofits. She is an Academy Award nominated documentary director. She directed the PBS Award winning documentary *Body & Soul: Diana & Kathy*. Short-listed for an Oscar, the film is celebrating its 10<sup>th</sup> anniversary and is being adapted into a musical. A 2012 Guggenheim Fellow award recipient, she is working on completing a trilogy of short documentary films that change our perceptions of ability. Ms. Elliott also makes training films that use high quality visuals and people with disabilities telling their own stories. Through her social media presence, she tweets regularly on topical disability news. She is also developing an app for Washington, D.C. visitors on the history of disability rights, and looking at empathy and disability through VR (Virtual Reality).

### **Khadijah Farmer**

Khadijah Farmer is a native New Yorker, born and raised in Hell's Kitchen. Khadijah began working in her field several years ago, supporting adults with Down syndrome and other neurodevelopmental disorders at a Day Services Program. This employment led her to opportunities supporting people in both residential and respite facilities. After several years of working in this environment, she was one of the first staff members at her previous agency chosen to spearhead a Community-Based Programming initiative, where she was able to support the group members to work completely in the community. This shift in environment afforded her the freedom to create meaningful community partnerships, which resulted in innovative opportunities for vocational and interpersonal skill building for the members of her group. One of Khadijah's greatest joys during that time was brokering communication and true understanding between community members and the people she supported. In 2014, the New York State Association of Day Service Providers recognized Khadijah for her significant work in the community by honoring her with the Service Provider of the Year Award. Khadijah joined the National Down Syndrome Society, the leading human rights organization for all individuals with Down syndrome, in May of 2017. In her role as the Community Outreach Associate, she supports the creation of meaningful partnerships with organizations across the country through the #DSWORKS Campaign. #DSWORKS is an employment initiative whose goal is to encourage corporations and businesses to invest in opportunities for people with Down syndrome to pursue careers.



### **Therese Fimian**

Therese Fimian is the Senior Research Manager at Source America Office of Strategy & Innovation and has worked in the disability and employment field for 20 years, establishing and overseeing national workforce programs, research and demonstration projects that promote economic self-sufficiency for individuals with disabilities. Ms. Fimian is currently part of the team that is directing the Pathways to Careers demonstration project, a national systems change employment initiative to ensure that youth and adults with significant disabilities can successfully obtain competitive, integrated, diverse employment options and achieve their career goals.

### **Kelly Friedlander**

Kelly Friedlander, MSW, MPA is a Partner at Community Bridges Consulting Group where she works on projects related to stakeholder engagement, advocacy, and developing innovative solutions to meet systems changes. She is the Project Director for the North Carolina Stakeholder Engagement Group, a cross-disability advocacy initiative focusing on shaping the long-term support and service systems through meaningful engagement and dialogue with policymakers.

### **Sheila Gritz-Swift**

Sheila Gritz-Swift serves as the Florida DD Council's Deputy Director of Programs, where she provides oversight and support for development, implementation and evaluation of the Council's Five-Year State Plan. In this role, she oversees approximately 40 initiatives designed to improve transportation, employment, elementary through postsecondary transition, self-advocacy, housing and the direct service provider workforce. Mrs. Gritz-Swift's background includes 25 years working in the field of exceptional student education as a practitioner, statewide trainer and Program Specialist for the Florida Department of Education with a focus on secondary and postsecondary transition. She served as the Council's Program Manager for Employment and Transportation for two years before becoming the Deputy Director of Programs in 2014.

### **Jessica Guerrero**

Jessica Guerrero is an actress, storyteller, and ComiCon aficionado. She graduated in 2008 from Southwestern University with a B.A. in Communication Studies and a Minor in Theatre Arts. Since then, she has been involved with Austin Nature and Science Center, San Antonio Independent Living Services, and Austin Public Library. She is currently an active participant in VSA Texas' *Opening Minds, Opening Doors* public speaker training project and has presented at the Texas Transition Conference, Texas Network of Youth Services Conference, Texas Parent to Parent Conference, San Japan, and IKKiCON, Austin's own Japanese Animation and Pop Culture Convention.

### **Heather Hardee**

My name is Heather Hardee and I am 26 years old. I live with my dad, stepmom and my step sister. I attended Conway Christian School and graduated in 2010. I have a learning disability and seizures. I want to become a nurse in the future because I like helping people and making people feel better. I like to be healthy by eating right and exercising. Fit for Life has helped me become independent and eat better and healthier. Some things in Fit for Life that I have learned are portion control, the importance of hydration, and the negative effects of fast food. My personal training was at Planet Fitness. I saw the last Fit for Life assistant help lead the team,

and soon I will take her place. As the new assistant I will help make exercising fun. I want to help make the class aware of making healthy choices.

### **Laura Henrie**

Laura Henrie is a Supervising Attorney at the Disability Law Center. She has worked at the DLC since 2007 and supervises work on the Center's Community Integration, and Employment teams. Ms. Henrie's practice has focused on litigating employment discrimination cases as well as policy efforts to support and expand community integration options for people with disabilities. Ms. Henrie also represents clients who have been denied services or equipment by Medicaid. Prior to law school, Ms. Henrie worked as a service provider to support individuals with I/DD. She has an adult brother with an intellectual disability and has a long standing commitment to disability advocacy. Ms. Henrie received her law degree from the SJ Quinney College of Law at the University of Utah.

### **Kelly Holt**

Kelly Holt was born and raised in southern California and moved to Utah in the early 2000's. She currently lives in Price in her own apartment surrounded by her two sisters, brother in-law and father. Her first exposure to advocacy started when she was introduced to the members of the Utah State Legislature in January 2003. In the months and years that followed, she has served as an elected member of the local and State People First of Utah, was a board member of both the Utah DD Council and the Utah Disability Law Center. Kelly testified to Utah State Health and Human Services on behalf of those on the "Wait List" and helped pass legislation in Utah to get the "R" word removed from state statute. She currently lends her expertise as the Chair of the Consumer Advisory Council at Utah State University, Center for Persons with Disabilities. Kelly has spoken locally and nationally on a variety of topics important to those with disabilities.

### **Celia Hughes**

Celia Hughes is the Executive Director of VSA Texas, the state organization on arts and disabilities. She has over 40 years of experience working in the arts as a teacher, producer, artist and administrator and has worked alongside people with disabilities for over 35 years. In 2011, Ms. Hughes participated with the beta testing of an online graduate course by Lesley College in Cambridge, MA on Curriculum Design for Arts Teaching and Learning, promoting the principles of Universal Design for Learning (UDL). She has developed and conducted professional development workshops for fine arts, general education and special education teachers in Texas for over 20 years, and since 2006 has offered workshops focused on integrating arts in special education and inclusive classrooms. In 2008, VSA Texas launched its New Media Arts program, experiential education and activities in video production, photography, animation and radio that has served a diverse group of transitioning youth, including individuals diagnosed with ASD. This program operates both in high school classrooms and out of school community art centers. The *Opening Minds, Opening Doors: Promoting Self-Advocates as Speakers* program, in operation since 2013, has helped create awareness of the abilities of all people through trainings and conference presentations. When she is not wearing her administrative hat, you will find her in the theater, providing live description of all things visual to people who are blind or have low vision.

### **Linda Kendall Fields**

Linda Kendall Fields, M.Ed., is a Clinical Assistant Professor with the Jordan Institute for Families at the University of North Carolina School of Social Work in Chapel Hill. She is the facilitator for the *Rethinking Guardianship: Building the Case for Less Restrictive Alternatives* Initiative.

During her 35-year career, Linda has led numerous government and community across the country. Among her accomplishments, she developed the Georgia Peer Support Training Curriculum and coordinated both the Georgia and North Carolina Nursing Facility Transition Grants. She remains actively involved with the state's Money Follows the Person Project and is providing technical assistance to North Carolina's "Supported Living: Making the Difference" initiative.

### **Russell Lehmann**

Russell Lehmann is an award-winning and internationally recognized motivational speaker, poet, author and advocate whose words have reached over 15 million people worldwide. Russell happens to have autism, and he sits on the Nevada Governor's Council on DD, is a board member for the Autism Coalition of Nevada while also chairing their statewide Youth Advisory Committee, is a founding member of the Kulture City Speaker's Bureau, an organization which spreads awareness and acceptance about autism, and is the Youth Ambassador for the mayor of Reno, Nevada, Hillary Schieve.

Russell showed signs of autism as a newborn, however he was not formally diagnosed until the age of 12 after suffering through 5 weeks in a lock down psychiatric facility. In 2011, Russell wrote a book titled "Inside Out: Stories and Poems from an Autistic Mind" which was featured in the LA Times, earned an Honorable Mention at the 2012 NY Book Festival, was read by Temple Grandin and won the award for Literary Excellency at the 2013 International Autistic People's Awards in Vancouver, Canada.

Russell currently travels the country spreading hope, awareness, acceptance, belief and tolerance while also setting his sights on erasing the stigma and stereotypes that come with having a disability. Russell's passion is to be a voice for the unheard, for he knows how difficult and frustrating it is to go unnoticed.

### **Katie Macklin**

Katie Macklin serves as the Senior Director of Advocacy & Executive Director Delaware for the Delaware Valley Chapter of the Alzheimer's Association. She earned a Bachelor of Science in Biology from Ursinus College and a Master of Public Administration with a specialization in Health Policy from the University of Delaware.

Through personal experience and her tenure of nearly a decade at the Alzheimer's Association, Katie has developed an understanding of the issues faced by the population of people with Alzheimer's disease and related disorders, as well as their families and caregivers. In her current role at the Chapter, she uses her background and experiences to advocate for improvements in the quality of care and services for individuals with dementia and their families and increased funding for research towards discovery of new treatments, ways to prevent the disease and ultimately a cure for Alzheimer's disease.

### **Pat Maichle**

Pat Maichle is the Director of the Delaware DD Council and a parent of an adult child with Down syndrome. Maichle has been advocating for people with disabilities for over 30 years in Delaware. She has served as the Director of the Delaware DD Council since 2001. Prior to that she had worked for the state government in the

developmental disabilities field, as well as for people with mental illness and substance abuse. Pat earned a B.A. in Psychology from the University of Delaware.

### **Kelly Mayo**

Kelly Mayo is the Food Services Director at the Legacy House of Ogden and Ashtin's Supervisor. Kelly has been an integral part of Ashtin's success at Legacy House and was an advocate for getting Ashtin employed after completing her internship.

### **Derrick Means**

Derrick Means is an EQUIP Leader from South Carolina! Derrick currently works at Spartanburg High School, Pizza Hut, and Able SC. He graduated high school from Union County High School in 2008. He graduated with his associates' degree from USC-Union in 2009 and received his Bachelor's degree in 2013. Derrick plays the bongos and the congas. He serves on the South Carolina DD Council and on the board with the Miracle League of Union County. He also plays baseball with the Miracle League of Union County. Derrick has one brother and one sister.

### **Jeffery S. Miller**

Jeff has held various policy related positions at Disability Rights Texas (DRTx) starting in 2006, including work in the areas of health care access, community integration, and special education. He currently focuses on a number of issues including voting rights, self-determination and alternatives to guardianship. In addition to extensive professional experience, Jeff is able to share his personal experiences as a father of a son with disabilities. Jeff received his law degree at University of Louisville School of Law and holds a B.A. in Speech Communication from the University of Houston.

### **Ashtin Miller**

Ashtin is a Pathways to Careers participant who successfully completed an internship at Legacy House of Ogden. Ashtin was offered a position as a Kitchen and Dining Aide with the Legacy House.

### **Claire Mantonya**

Claire Mantonya has deep Ohio State Buckeye roots having grown up in Ohio and she has a Master's degree from The Ohio State University. Her undergraduate degree in Natural Resources is from the University of Michigan and Go Blue is the cry every fall during football season.

Claire moved to Utah in 1996 and has worked exclusively in the disability community since as a provider with Easter Seals, staff at the DD Services agency, and at the Utah DD Council since 2004. She has directed the Council since 2006.

### **Andrew Morris**

Andrew Morris is a Policy Analyst in the Center for Policy and Evaluation at the Administration for Community Living at the United States Department of Health and Human Services. Andrew has an educational background in Public Health and Psychology. While at the Administration for Community Living, Andrew has focused policy issues relating to disabilities, health care, long term care, durable medical equipment, health reform, providing policy technical assistance to grantees, and writing regulations and guidance for the Developmental Disabilities Assistance and Bill of Rights Act of 2000. Prior to coming to HHS, Andrew was Director of Government Relations for the United Spinal Association, a nationwide organization that advocates for people

with spinal cord injuries. While at United Spinal, Andrew focused on health reform, Medicare, Medicaid, durable medical equipment, and other related policy issues that promoted integrated community living. Andrew also served on the Board for the Consortium for Citizens with Disabilities, a coalition of over 100 national disability groups during that time. Additionally, Andrew served on the Steering Committee and Board for the Independence Through Enhancement of Medicare and Medicaid (ITEM) Coalition.

Andrew is originally from Oregon, where he completed training in the developmental disabilities field through the HRSA funded Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program at the Oregon Health & Science University (OHSU), in addition to a Policy Fellowship at the Association of University Centers on Disabilities in the Washington, D.C. area. After his training in the disability field he worked for several years in Government Relations at OHSU lobbying on behalf of the University and educating policy makers on behalf of the University Center for Excellence in Developmental Disabilities located within the University. Andrew started his career at the Oregon State Legislature working as Committee Staff on health care and related issues. Andrew has a Master's in Public Health from Portland State University in Portland, Oregon and a bachelor's degree in Psychology from Corban University in Salem, Oregon.

### **Diane Owens**

Diane Owens was born and raised in Malone, NY. She received her Bachelor of Arts degree in 2000 with a major in English Writing and Literature and a minor in Communications. In 2010, Ms. Owens began her Masters of Science Degree in Counseling Studies and Human Services and graduated with honors. In 2013, she was hired as an ABA therapist for SOS Health Care, Inc. in Myrtle Beach. Since being employed with SOS Health Care, Diane has been promoted to a lead ABA therapist and has also taken on the role of program coordinator for their Autism Community Education (A.C.E.) program, Fit for Life, and she is the program coordinator for a grant received from the Bunnelle Foundation that provides special needs activities and education in Georgetown County which is a neighboring county of Myrtle Beach. Diane was chosen by her boss to be the Program Coordinator for Fit for Life due to her healthy lifestyle changes. Over the course of her lifestyle change, Ms. Owens learned a great amount about fitness, proper form, weight loss, weight maintenance, healthy eating, portion control, hydration, and eating for your body type and blood type. She visited various doctors and wellness centers to learn and implement scientific procedures to obtain maximum wellness. While doing Fit for Life, Ms. Owens has been able to educate and empower teens and young adults on the importance of fitness, nutrition and overall wellness and has seen a big change in the quality of life of this young adults.

### **Santa Peña**

Santa Peña currently serves as the Director of Counseling at South Texas College and has over 16 years of experience in higher education. Since 1999, she has performed the function of a Counselor, Lead Counselor, Coordinator of Counseling, and now Director of Counseling. Mrs. Peña leads and facilitates academic counseling, career counseling, mental health counseling and student disability services for South Texas College. She ensures the services are in support of the instructional programs and in keeping with the philosophy and purpose of the College. She provides systematic support services to help students reach their educational, personal, and career objectives. She directs Project HIRE events for South Texas College. Mrs. Peña trains, orients, assigns, supervises, and develops professional staff in accordance with College policy, procedures, and practices to ensure compliance with the highest possible quality performance standards. She

evaluates the effectiveness of student services and programs using appropriate data. She analyzes counseling and guidance procedures and techniques to improve quality of service. Mrs. Peña interacts with school districts, local colleges/universities, community groups, social service organizations, and governmental agencies to improve student services. Mrs. Peña serves on numerous college-wide committees and task forces with a focus on the student pathway to completion thus improving the momentum to graduation and removing barriers to success.

Mrs. Peña's educational background includes a Bachelor of Science in Biology with Secondary School Certification and a Master of Education in Counseling & Guidance from the University of Texas Pan American. Mrs. Peña is a Licensed Professional Counselor-Supervisor, a Certified Anger Resolution Therapist and is certified for Satori Alternatives to Managing Aggression (SAMA). Mrs. Peña is currently the board chair of the Rio Grande Valley Council-UNIDAD Coalition and is the current president of the Rio Grande Valley Chapter of the Texas Association for Play Therapy. Mrs. Peña is an active member of the Texas Association Against Sexual Assault and the National Behavioral Intervention Team Association. Mrs. Peña values community engagement; she has served the Rio Grande Valley community as a Roma Housing Authority board member, Valley AIDS Council board member, and on the Child Protective Services Community Review Team.

### **Sarah Pope**

Ms. Pope received her degree in Social Work in Kent, England, where she held positions supervising and developing programs and treatment plans for people with disabilities. While residing in NJ, Ms. Pope held a position as a group home manager for the Division of Developmental Disabilities. She has worked as a Residential Social Worker for DDSN in South Carolina and as an ABA consultant and parent mentor. She also served as Director of Parent Educator Resource Services for Horry County Schools. In 2010, Ms. Pope joined SOS Health Care as Executive Director and has successfully grown and expanded programs there. She has served as Chair of the SC Advisory Council for Exceptional Children, Vice President of the Autism Advocate Foundation, and has served on the Board of Directors for the SC Autism Society, and is a past President of the ARC of Horry County. Ms. Pope has two sons with Autism, Ben is 22 and Liem is 15.

Ms. Pope created the Fit for Life Program because of the changes she noticed with her own children when they engaged in physical activities. They had a noticeable increase in attention; they enjoyed working together to create exercises to tone various muscle groups. Liem especially enjoyed seeing how toned his body became as he challenged himself with extra sit ups and push-ups. His interest in running gave him a new social outlet and an opportunity to meet others interested in 5Ks.

The Pope family members are all on restricted diets due to various health issues. Ms. Pope's awareness about healthy eating topics is often common place conversation in all of the SOS Health Care Programs. The core of nutritional education is woven into our Social Skills, Life Skills, and Camp Programs. Secondary health issues are common place in the population SOS serves. We are trying to get ahead of that and help families as much as possible with programs like Fit for Life.

### **Erica Powell**

Erica Powell is the EQUIP Coordinator for Able South Carolina. Erica graduated with a Bachelor's degree in Psychology, with a minor in Sociology from Clemson University in 2015. At Clemson, Erica was a scholarship student athlete as a cheerleader for the Tigers' football, basketball, and national competition team. As a



young adult with a disability herself, Erica is passionate about empowering other youth with disabilities! Erica lives in Greenville, South Carolina and enjoys fitness, family, friends, and Clemson football!

### **Sonia Quintero**

Ms. Sonia Quintero has a bachelor's degree in Speech Pathology and Hearing – Impaired Therapist *Fundación Iberoamericana INPI* - University Colombia, S.A and she is a Certified Supported Employment Specialist from Virginia Commonwealth University.

Ms. Quintero has worked over 9 years as a Deafness Resource Specialist at Communication Access Ability Group, a program funded by the Health and Human Services Commission Office for Deaf and Hard of Hearing Services. She works with people that have hearing loss, their families, state, local and federal agencies, courts, schools/colleges, law enforcement, public and private businesses and service organizations. She actively addresses attitudinal and cultural barriers of individuals with disabilities, with employers and community organizations; promoting equal opportunities for persons with disabilities in the workplace, and the educational sectors.

Ms. Quintero has been able to serve as an advocate, introducing strategies for the interactive process to obtain job accommodations. Numerous workshops and trainings were provided on disability awareness, removing barriers and fears in the hiring process or retraining their employers. Ms. Quintero has been supporting underserved individuals with developmental disabilities with their transition plan into school or work environment, helping to empower them with knowledge on their rights in order to enhance their lives to become more self-sufficient, self-confident and as independent as possible.

### **Paulena Rymer**

Paulena Rymer has works with TURN Community Services since 2001 and has held several positions with the company, currently as a Program Coordinator. First and always, she is a sister of a young lady with FASD and autism along with other underlying disabilities. Alongside other family members, she has helped her sister transition through loss, school changes and daily relationships with others. Her sister is at the age she is transitioning into adulthood, and Paulena is advocating for her sister's best interest.

### **Jeff Sheen**

Jeff Sheen is the Policy Analyst/Project Director at the Center for Persons with Disabilities, Utah State University. He leads Senator Hatch's Utah Advisory Committee on Disability Issues. Jeff's research interests include: young adults with intellectual disabilities and transition to postsecondary education, vocational rehabilitation counselor training, mindfulness based interventions in rehabilitation counseling, and the psychospiritual aspects of disability. Some of Jeff's current projects include the Aggies Elevated Postsecondary Education Demonstration Project, and the Utah Disability Health Program. Jeff also serves as a CPD Policy Analyst. He is a consultant on several other state and national projects and is an adjunct faculty member for the USU Department of Psychology and the Department of Sociology, Social Work, and Anthropology.

### **Nessie Siler**

Nessie Siler is an engaged advocate from Manteo, North Carolina. She is a member of the NC Stakeholder Engagement Group. She is also a Partners in Policymaking graduate and member of the North Carolina Council on DD.

### **Andrew Sperling**

Since 1996, Andrew Sperling has served as Director of Legislative Advocacy for the National Alliance on Mental Illness (NAMI) – the nation’s largest organization advocating on behalf of people living with serious mental illness and their families. Prior to joining the NAMI staff, he served as a Legislative Assistant for several members of the US House of Representatives. He has also served on the Board of the Consortium for Citizens with Disabilities (CCD).

### **Amy Stapley**

Amy Stapley is the Program Manager at SourceAmerica Pathways to Careers. Before joining Pathways national team, Amy worked for Pathways to Careers at PARC in Clearfield, Utah as part of the original Pathways team. Amy has a passion for working with individuals with disabilities and looks forward to expanding career opportunities to many more individuals across the nation.

### **Eric Stoker**

Mr. Eric Stoker lives with his family in West Jordan, Utah and is employed by the Utah DD Council as the information specialist. He received the Champion of Equal Opportunity Award from NACDD in 2014. He has served on the Utah Parent Center Board of Directors, People First of Utah Board of Directors and the Consumer Advisory Council at Utah State University representing the voice of self-advocates. Eric has spoken nationwide about issues that affect people with disabilities, autism and his life experiences.

### **Beth Swedeen**

Beth Swedeen is the Executive Director of the Wisconsin Board for People with DD. She also has a delightful daughter with disabilities living the dream with the help of some amazing home and community-based supports (HCBS!).

### **Erin Taylor**

Erin Taylor is a mother of five teenagers and is originally from Costa Rica. She is the Adult Advocacy Coordinator at the Oklahoma DD Council, overseeing the Partners in Policymaking program and numerous legislative and policy priorities. Erin holds a PhD in adult and higher education and is a Leadership Education in Neurodevelopmental Disabilities Fellow.

### **Ann Trudgeon**

Ann Trudgeon is the Director of the Oklahoma DD Council, a federally-funded state agency administratively located within the Oklahoma Department of Human Services. The Council is a systems advocate that provides training to individual and other systems advocates; funds model demonstration programs and disability-based studies; monitors and informs public policy development; and promotes the inclusion of people with I/DD in all aspects of life – work, play, school, and worship.

Ms. Trudgeon joined the Council staff in 1989 as its Grants Manager and Planning Director and became its Director in 1993. She holds a bachelor’s degree in Political Science from Smith College; and has been appointed and elected to several state and national leadership positions within the field of developmental disabilities.

### **Julie Weinberg**

Julie Weinberg currently serves UnitedHealthcare Community & State as a Director for Strategy and Health Policy. Julie has over 25 years of experience in Medicaid in both the public and private sector. After spending 17 years with the New Mexico Medicaid fiscal agent where she was involved in all aspects of the operation, Julie joined the New Mexico Human Services Department's Medical Assistance Division (NMHSD) as Deputy Director of Medicaid. In 2010, she became the Medicaid Director, a position she held through 2014. During her tenure at NMHSD, Julie led the agency through numerous MCO procurements; an MMIS/fiscal agent procurement; implementation of an MLTSS program; the design, negotiation and implementation of an 1115 global waiver; the design and implementation of an innovative comprehensive managed care program; and the expansion of Medicaid. In 2015, she returned to the private sector where she worked for Optum State Government Solutions as an executive client manager for its data warehouse customers. Julie has been serving as Director for Strategy and Health Policy since joining UnitedHealthcare Community & State in late 2015. Julie is a graduate of the University of New Mexico. She was a 2012 fellow of the Medicaid Leadership Institute sponsored by the Robert Wood Johnson Foundation and is a Robert Wood Johnson Foundation fellow. She lives in Santa Fe, New Mexico.

### **Sara Weir**

Sara Weir is the President of the National Down Syndrome Society in Washington, D.C. Weir is a Kansas native and has been fighting for the rights of people with Down syndrome for over two decades. As President of the NDSS, Weir oversees the organization's mission, vision and administration, which is the largest nonprofit in the United States dedicated to advocating for people with Down syndrome and their families.

### **David Whalen**

David Whalen has worked in the field of disabilities since 1986, founding Disability Awareness Training in 2004. He has presented to over 600 audiences. Dave spent 17 years at Opportunities Unlimited of Niagara serving individuals with developmental disabilities. He is President of the Williamsville Special Education PTSA, Chair of the Town of Amherst's committee on disabilities, member of the Erie County Disability Advisory Board, and recently concluded a term on the NYS Independent Living Council.

In 2010, Dave and Niagara University received a NYS DDPC grant to develop Disability Awareness Training for First Responders. The program received a similar grant in Missouri. In October 2015, NYS DDPC awarded NU a three-year grant to address proper response to individuals with disabilities in emergencies. In 2011, David accepted an invitation to the White House for an historic MOU signing between FEMA and the National Disability Rights Network. He also accepted an invitation to join the International Association of Chiefs of Police (IACP) focus group, *Mental Health of Arrestees and How It Impacts our Officers*. Dave attended the Senate Hearing *Law Enforcement Responses to Disabled Americans: Promising Approaches for Protecting Public Safety*. He was also recognized for his consult with the Department of Justice's Community Relations Services for work on law enforcement disability awareness training. In April 2015, he became a FEMA-certified Access and Functional Needs Trainer. Western New York Deaf Access Services awarded him Deaf Advocate of the Year in 2016.

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## **National Association of Councils on Developmental Disabilities (NACDD)**

1825 K Street, NW, Suite 600  
Washington, D.C. 20006

Phone: (202) 506-5813

Fax: (202) 506-5846

E-mail: [info@nacdd.org](mailto:info@nacdd.org)

NACDD: [www.nacdd.org](http://www.nacdd.org)

ITACC: [www.itacchelp.org](http://www.itacchelp.org)

The Art of Impact: [www.startyourjourney.org](http://www.startyourjourney.org)

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Donna A. Meltzer  
*Chief Executive Officer*  
(202) 506-5813 ext. 103  
[dmeltzer@nacdd.org](mailto:dmeltzer@nacdd.org)

Sheryl Matney  
*Director of Technical Assistance*  
(202) 506 5813 ext. 148  
[smatney@nacdd.org](mailto:smatney@nacdd.org)

Angela Castillo-Epps  
*Technical Assistance Specialist*  
(202) 506 5813 ext. 100  
[ACastillo-Epps@nacdd.org](mailto:ACastillo-Epps@nacdd.org)

Deanna Hartzman  
*Communications Associate*  
(202) 506-5813 ext. 102  
[dhartzman@nacdd.org](mailto:dhartzman@nacdd.org)

Robin Troutman  
*Deputy Director*  
(202) 506-5813 ext. 105  
[rtroutman@nacdd.org](mailto:rtroutman@nacdd.org)

Cindy Smith  
*Director of Public Policy*  
(202) 506-5813 ext. 104  
[csmith@nacdd.org](mailto:csmith@nacdd.org)

Jessica Misilo  
*Administrative Operations Assistant*  
(202) 506-5813 ext. 101  
[jmisilo@nacdd.org](mailto:jmisilo@nacdd.org)









# NACDD

National Association of Councils  
on Developmental Disabilities

**NACDD serves as the national voice of state and territorial Councils on Developmental Disabilities. We support Councils in implementing the Developmental Disabilities Assistance and Bill of Rights Act and promote the interests and rights of people with developmental disabilities and their families.**

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